

CHARTER PROJECT TEAM MEETING

DSHS AUSTIN, M739 (BOARDROOM)

FRIDAY, FEBRUARY 1, 2008

MEETING NOTES

ATTENDEES:

<i>Sandra Billings</i>	√	<i>Sister Mary Nicholas Vincelli</i>	√
<i>George R. Buchanan</i>	√	<i>Morgan Walthall</i>	
<i>Donna Claeys</i>	√	<i>Don P. Wilson</i>	√
<i>Margaret Drummond-Borg</i>		<i>Jerald L. Zarin</i>	√
<i>Alice Gong</i>	√	<i>Margaret Bruch</i>	√
<i>Jose L. Gonzalez</i>	√	<i>Sberry Clay</i>	√
<i>Charleta Guillory</i>	√	<i>Mirsa Douglass</i>	√
<i>Cheryl Hermerath</i>	√	<i>Eldridge Hutcheson</i>	√
<i>Scott D. McLean</i>		<i>David R. Martinez</i>	√
<i>Francisco Ramirez</i>	√	<i>Jann Melton-Kissel</i>	√
<i>John Saito</i>	√	<i>Susan Neill</i>	√
<i>Eileen Sheridan-Shayeb</i>		<i>Sharon Newcomb-Kase</i>	√
<i>Reid Sutton</i>	√	<i>Susan Tanksley</i>	√
<i>Larry Sweetman</i>	√	<i>Donna Williams</i>	√
<i>Brad Therrell</i>	√	<i>Susan Snyder</i>	√

TIMELINE

02/08/08	Distribute TNSPMP Kick-Off meeting notes for review.
02/15/08	Distribute the TNSPMP plan and work breakdown structure for review.
02/22/08	Hold a conference call to review the TNSPMP plan.
02/27/08	Deadline to provide comments and input on TNSPMP plan.
02/29/08	Obtain official sign-off and approval to move forward with TNSPMP plan.
04/11/08	Distribute a draft of a summary report discussing gaps and barriers. The summary report will include an internal assessment of DSHS Newborn Screening program using PEAS, a short discussion on the National Newborn Screening and Genetics Resource Center's (NNSGRC) review and information found from literature searches.
04/17/08	Hold TNSPMP Quarterly Meeting to review summary report, determine the area of focus for performance measures, and to review proposed performance measures.
09/28/08	End of first year project period

GOALS FOR MEETING

After opening statements and introductions, participants commented on the expectations of the meeting.

- ❖ Learn process of newborn screening in its entirety from drawing the specimen, screening, through notification of physicians and parents, to treatment and care of infants.
- ❖ Learn the relationship of this project to the Program Evaluation and Assessment Scheme (PEAS).
- ❖ Learn what can we do differently? How will it impact the system?
- ❖ Gain a better understanding of follow-up mechanisms including initial notification or call to parent.
- ❖ Move agenda forward to screen for 28 disorders including Cystic Fibrosis (CF).
- ❖ Understand the newborn screening process and address the timing of first screen (access). Screens are not done at the appropriate time.
- ❖ Learn procedures of initial call and parent contact.
- ❖ Understand method for educating health care providers.
- ❖ Concerned with laboratory technique, specifically false-positives.
- ❖ Network

BRIEF OVERVIEW OF PROJECT CHARTER

Dr. Neill briefly discussed the goal and scope of the TNSPMP.

The goal is to provide evidence-based performance measures to the medical community in Texas that can be used nationwide to identify opportunities to improve patient care for newborns identified with congenital and heritable disorders. The scope of the performance measures is limited to pre and post analytical activities, not testing activities.

ASSESSING THE CURRENT SYSTEM

Participants shared points on the pros and cons of the current newborn screening system.

WHAT'S NOT SO GOOD?

- ❖ Newborn screening program is not valued by parents and providers. The lack of understanding and awareness across the system may influence the lack of value for the newborn screening program.
- ❖ Adequate financing is needed to cover newborn screening activities including education, case management and follow-up activities.
- ❖ Cystic Fibrosis screening is not in place. (Texas has the largest population of affected children with this inherited disease.)

- ❖ Lack of advocacy efforts with the legislature. Research and findings are needed to support and influence policy. A strategic process is needed to make decisions for the newborn screening system.
- ❖ Not every infant is screened for newborn disorders (including newborn hearing screening). Approximately 90 to 95 percent of infants receive a first screen. Of those, approximately 90 percent receive a second screen. Need a method to coordinate with birth records to determine who has/has not been screened.
- ❖ Lack of access to confirmatory testing.
- ❖ Hospitals need a way to know how they are performing.
- ❖ Lack of an effective courier system to ensure timeliness of specimen transport and delivery to the state laboratory.
- ❖ Providers are unaware of how to access DSHS or national information on newborn screening.
- ❖ Lack of adequate training for regional staff coupled with their multiple responsibilities outside of newborn screening program.
- ❖ Lack of specialists and lack of access to specialists for newborn screening disorders.
- ❖ Psycho-social barriers exist for families which lead to diagnosed infants not receiving proper follow through on treatment and care.
- ❖ Input from advisory committees and advisory boards for DSHS is diminished. Input from subject matter experts and external entities is lacking or non-existent. DSHS has discontinued travel reimbursements for advisory members.
- ❖ Information on diagnosis of affected infants is not communicated back to DSHS in a timely manner.
- ❖ Not enough information is made available to providers about disease specific guidelines.
- ❖ Sick cell and other newborn screening disorders lack proper follow-up, especially for long term. "What is the condition of the baby 10 years from now?"
- ❖ Mobility of families poses a challenge to track screening.
- ❖ Lack of available information on disorders that are not screened in Texas and where families can obtain that screening.
- ❖ Lack of referrals to Early Childhood Intervention Services (ECI) which is the statewide program for families with children, birth to three, with (or at risk for) disabilities and developmental delays.
- ❖ The size and demographics of Texas poses many challenges for the newborn screening program.
- ❖ Texas has a high percentage of children (per capita) relative to other states.
- ❖ It is difficult to track and monitor children transferring across state lines and the Mexican border.

- ❖ There are many undocumented children, which causes problems when trying to track abnormal results, ensure screens are obtained, etc.
- ❖ Lack of information regarding the impacts on screening results of premature babies, those on total parenteral nutrition (TPN), those who had blood transfusions, etc.
- ❖ Too many repeated screens due to TPN, premature births, blood transfusions, etc.
- ❖ Not doing full scan for tandem mass spectrometry – could pick up more disorders
- ❖ Lack of health care provider education.
- ❖ Lack of coordination at birth to identify every child. Need to have linkage between birth certificates and newborn screening records. Every birth certificate should have newborn screening report.
- ❖ Hospital turnaround times to send specimens to the laboratory are not timely. Hospitals may be batching specimens before sending off.
- ❖ DSHS needs adequate or better feedback/notification from physicians when diagnosed infants are treated. Processes in place lack standardization.
- ❖ Eligibility issues with special health care needs: Medicaid, Children with Special Health Care Needs (CSHCN) - an insurance provider, Texas Health Steps Comprehensive Care Program (THSteps CCP) which provides extra benefits for Medicaid clients, etc.

WHAT'S GOOD?

- ❖ DSHS processes a high volume of specimens, approximately 800,000 per year. The laboratory screening turnaround time is very good considering the volume of specimens.
- ❖ DSHS staff shows dedication and enthusiasm.
- ❖ Excellent website which nicely outlines material, is easily accessible, organized presentation, and addresses a diverse audience.
- ❖ Dedication of providers to screen and follow through with infants.
- ❖ DSHS commitment to improve newborn screening program and the overall system.
- ❖ Having a world class, state-of-the-art laboratory making pre and post analytical issues easier to address.
- ❖ Willingness of DSHS staff to outreach and educate.
- ❖ Free continuing education credits (CE) and continuing medical education (CME) credits.

VISION OF SUCCESS

Participants shared their vision of success for the newborn screening system.

- ❖ A system that works for everyone
- ❖ A way or ways to identify success
- ❖ Setting the standard by which others measure

- ❖ Positive role model for other states
- ❖ Identify and treat diagnosed infants
- ❖ A knowledgeable community (consumers, health care providers, nurses, physicians, etc.)
- ❖ Understand barriers and have developed strategies to address and/or overcome barriers
- ❖ System that “picks up” diagnosed infants prior to onset
- ❖ A system where every player knows what to do, when, and how to do it. Players know how the whole system works.
- ❖ A screen for every birth certificate
- ❖ An information system that works

CATEGORIZING THE ISSUES AND CHALLENGES

Participants categorized the issues and challenges through an exercise that involved writing the topic areas on separate pieces of papers and silently grouping these on the wall as a group. Not listed in any particular order, the following categories were established

SIZE AND DEMOGRAPHICS OF TEXAS – OVERARCHING CHALLENGE

BUDGET AND FINANCE

- Include CF in screen
- overall financing of program
- legislative advocacy
- access to confirmatory testing
- external advisors to DSHS are lacking
- ratio/percent of kids in Texas

SYSTEMS PROCESSING

- Human medical resource
- undocumented children
- coordinate with birth record
- border issues (Mexico & other border states)
- not every baby screened
- lack of courier system
- hospital turnaround time (sample to lab time)
- where do families go for diseases not screened in Texas
- opportunity for outside professional organization input

FOLLOW-UP

- Family psychosocial and economic issues to follow through
- mobility of families vs. screening
- sickle cell & other disorders lack of follow-up (where is baby 10 years from now)
- untimely information for diagnosis and outcome
- lack of specialists
- multiple responsibilities of regional staff
- lack of referrals to ECI
- lack of access to specialists
- eligibility for Medicaid/CSHCN/THSteps CCP

EDUCATION

- Lack of parent awareness
- parents and provider care physicians (PCP) don't value NBS
- providers don't know how to access info from DSHS/national resources
- lack of regional staff training
- lack of health care provider education
- not enough info to providers about disease specific guidelines
- impacts on screening (premature babies, tpn, transfusions, etc.)

PROJECT ROLES AND RESPONSIBILITIES

Mirsa Douglas briefly commented on the roles and responsibilities of the external stakeholder group.

Roles and responsibilities will be outlined in the project plan to be delivered several weeks after the meeting. Examples are attending quarterly TNSPMP Team meetings, participating in conference calls, reviewing documents written by the internal DSHS team, providing overall input, providing access to pertinent information, prioritizing proposed performance measures, providing recommended uses of performance measures, etc.

TEAM WORKING METHODS AND GROUND RULES

Participants agreed on a basic method for making group decisions as the project moves forward.

- ❖ 80 percent consensus method – When participants are 80 percent “OK” with the decision, it is acceptable to move forward with the decision.
- ❖ Decisions are made in person.
- ❖ There is only one meeting; No side conversations or side meetings.

PARKING LOT ISSUES

Topics of financing and funding of the newborn screening program was placed in the parking lot issues. Discussion points are shown below.

- ❖ A huge variance exists between the fees from state to state.
- ❖ Texas legislature provides funding for under-insured and uninsured. 60 percent of the births are Medicaid funded.
- ❖ Start-up funding is necessary because revenue streams are collected on a reimbursement method. Newborn screening cards marked as 'Medicaid/Charity' are processed quarterly to validate eligibility. 'Paid' cards are paid by the ordering physician. Payment for newborn screening 'Paid' cards is due 120 days after shipment.
- ❖ Fees were determined based on the cost of the testing, education efforts, and case management activities within DSHS. The fee changed from \$19.50 to \$29.50 per card where \$3.00 is now allocated to case management activities.
- ❖ To take advantage of funding synergies, the newborn screening program is funded through other sources such as Title V. Although Title V funding is decreasing, some of these funds are used to support laboratory, case management and follow-up activities.
- ❖ Barriers exist to increase fees: Provisions and interpretation in the law do not allow increases and TMA and THA stakeholder input would not tolerate fees over \$30.00
- ❖ A cost analysis would be beneficial to understand the true costs between the laboratory and case management activities. Typically, there is a 50-50 split of allocated costs between laboratory and case management activity. Fees are as high as \$175.00 (ex. Alabama). Texas fees are on the low end of the national range.

MEETING PLUS/DELTA (FEEDBACK)

Participants shared thoughts about what they liked and didn't like about the meeting.

CHANGES

Did not like the table cluster layout

Would have preferred a room arrangement such that tables are situated in a circular layout so all seats have an equally good view of all participants.

POSITIVE FEEDBACK

Appreciated overview of the newborn screening program

Good orchestration and involvement of meeting

Good movement and activity for participants

Delicious cakes

Effective facilitator

Well-planned meeting by staff, good preparation

Nice selection of room and location